

When The Bough Breaks

Parental Perceptions of Ethical Decision-Making in the NICU

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Some of the parents in my Community Health practice were assigned to follow-up home visits since their infants resided in the neonatal intensive care unit (NICU) immediately after birth, or later after some critical incident. As I talked to these parents, mostly the mothers, their perception of events in the NICU did not match my expectations based on a theoretical examination of high-risk infant ethical dilemmas during my doctoral program. Continuing discussion with this type of patient aroused my curiosity about the discrepancy between the NICU experiences and the discussions in the bioethics literature.

Research Goals

The major purpose of the project was to explore and describe the ethical dimensions of the NICU experience from the parents' perspective at each of three points in time: pre-discharge, 6 months post-discharge and 4 years post-discharge.

Moral orientation of the parents would also be identified through the use of specific questions related to the theories of Kohlberg and Gilligan.



Observing undergraduate students as they get some first-hand clinical experience in NICU.

Gathering the Evidence

Research Design: qualitative, exploratory, descriptive.

Semi-structured interviews were scheduled with parents after they were approached by the staff in the targeted NICU. Information about the project was provided to prospective participants. Permission was sought for the principal investigator to contact them. Interviews were tape-recorded and transcribed verbatim.

For the primary analysis, interviews were examined and various strategies were applied to identify major themes among the participants as well as relevant outlier information. In the secondary analysis, moral orientation of the parents was determined based on the work of Lyons and Gilligan.

Even later, a theoretical analysis from a feminist perspective was completed and a separate description of themes from the fathers' perspectives was developed.

Findings

Pre-discharge

Parents described a passive role when their infant(s) was in the NICU. We labeled this *Medicalization of parenting*.

6 Months Post-discharge

After discharge there was a dawning realization of the scope of decision-making that had occurred and its impact on their present and future lives. This phase was labeled *Emerging ethical consciousness*.

4 Years Post-discharge

Finally for most of the parents, they understood that they had to let go of what might have been in order to live life to its fullest in the present. Based on the exact words of one participant, we called this phase *Life goes on*.

Moral Orientation

Given the theoretical framework for this analysis, orientation was described in terms of a caring voice or a justice voice. Both voices were present in the majority of the participants' interviews, while the justice voice predominated in both mothers and fathers.

Resources

Numerous references were accessed over the course of the years since the project's inception in 1985. These can best be reviewed by examining the Bibliography of the book which describes the entire study, *When the Bough Breaks* (2002). [The book is available from University Press of America.](#)

All of the articles produced over the course of the project are available in various professional journals. They are included in the Bibliography of the book listed above or they can be identified by searching an index such as CINAHL or Medline by author's name.

The project was also featured as the cover story for *Creighton University Magazine Summer 2003*.

One parent, not in this study, wrote an interesting essay about her experience with a disabled child, [Welcome to Holland.](#)

[Some of the work of Helen Harrison, a longtime advocate for parents would also be relevant to this project.](#)

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Examples of Student Work

Graduate students the School of Nursing take a required bioethics course. As part of that course work, some students elect to continue the investigation of ethical issues in the NICU.

[*Bridging the Gap Between Healthcare and Parents*](#)

[*The Gray Zone of Viability*](#)